

Juvenile Huntington's Disease (JHD): Educational Options

National Conference

June 6, 2009

Phoenix, Arizona

Marta Urbina

AZ Department of Health Services, Office for Children
with Special Health Care Needs

602-542-2528 urbinam@azdhs.gov

Rita Kenison

Raising Special Kids

Parent Training & Information Center for AZ

602-242-4366 ritak@raisingspecialkids.org

Huntington's Disease Society of America

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2009 HDSA convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

Presenters' Disclosures

Marta Urbina

Rita Kenison

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose or list

Learning Objectives

- Parents will learn essential educational options for children with JHD
- Parents will learn the importance of team decision-making with school staff
- Parents will learn about accommodations available for support in school settings

School Environment Outcomes

A safe place that:

- Supports learning and social interactions with peers
- Supports independence to the degree possible
- Provides educational and related services and interventions as needed

Successful Support Framework

- Clearly identify the types of supports your child needs in educational settings
- Educate staff on JHD and how it affects your child in particular
- Develop formal plans for staff to follow to ensure safety and needed supports
- Build a strong working relationship with school staff at all levels
- Maintain two-way communication

Team Decisions Determine Support to be Provided

- Options require meeting eligibility criteria
- Evaluations or assessments of existing reports, prior history and current functioning are reviewed against criteria
- Some additional assessments may be needed to determine “educational needs”
- Documentation and important records presented help justify educational needs

Options for Support at School

- Section 504 Plan for “reasonable accommodations” in educational settings
- Special Education and/or related services with an Individualized Education Plan (IEP) for modifications to curriculum
- Behavior Intervention Plan
- Health Plan for Chronically Ill provision
- School Health Plan or Emergency Plan

Section 504 Plan

- Request a Section 504 evaluation
- Evaluation with statement of a disability that “substantially limits life activities” (e.g. learning)
- 504 meeting with relevant school staff
- Develop a 504 Plan listing “reasonable accommodations” in school settings
- Give copy of 504 Plan to ALL staff expected to implement it

Example Accommodations

- Reduced homework assignments
- Extend time for completing tests
- Shortened school day
- Behavior Intervention Plan (with Positive Behavioral Supports)
- Assistive Technology (low tech-high tech) to access general education curriculum
- Designate safe haven for “cooling off”
- Organizational planner and checklists
- Emergency Health Plan (e.g. for seizures)

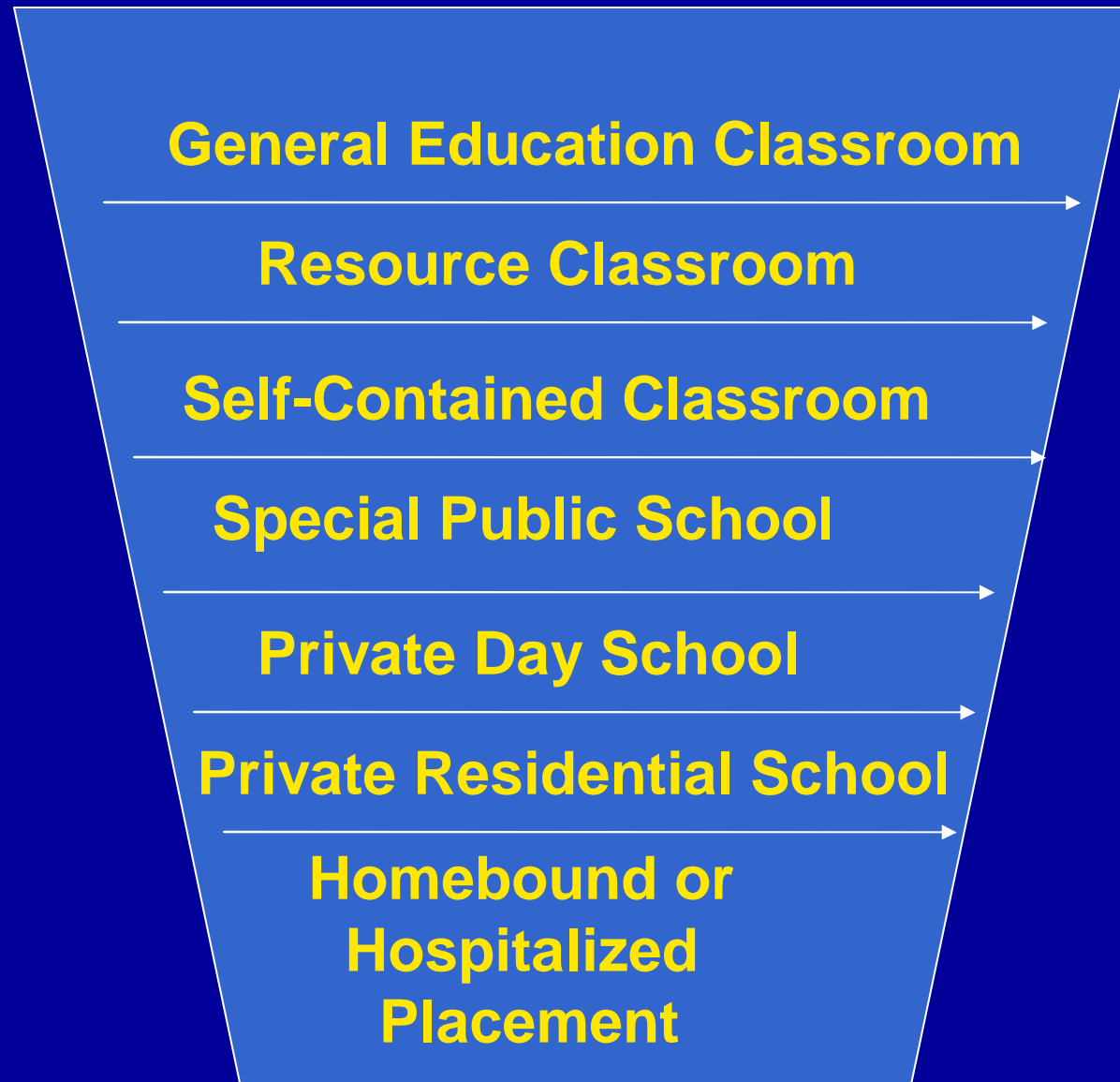
Special Education

- Evaluation to determine eligibility (e.g. Other Health Impairment, Learning Disability, or Emotional Disability)
- Development of an Individualized Education Program (IEP) by a team
- Modifications to general education curriculum
- Specialized instruction and/or related services in Least Restrictive Environment

Parental Rights in Special Education

- Schools give Prior Written Notice for major changes before implementing
- Parents can disagree – recommend putting requests for appeals in writing
- Decisions are to be made by the team, including parents
- Formal due process procedures are followed through the chain of command

Continuum of Placement Options



Related Services to Consider

- Speech Pathology
- Occupational Therapy (fine motor skills)
- Physical Therapy (gross motor skills)
- Counseling
- Adaptive P.E.
- Specialized Transportation
- Behavioral Interventionist
- Assistive Technology

Primary Elements in IEPs

- Present Level of Academic Achievement and Functional Performance
- Considerations of Special Factors (behavior, communication, assistive technology, etc.)
- Goals tied to needs and state standards
- Services and Related Services to be provided
- Supports for School Personnel (e.g. training)
- Accommodations in general classroom

Chronically Ill Provisions (in AZ)

- Medical certification from a physician that child will not be able to attend school for at least 3 school months (60 school days)
- Written plan outlining how school assignments will be given/submitted
- Statement of how school grades and school credit will be determined
- Responsibilities of school and parent
- Revise at end of timeline if needed

Emergency Plan or Health Plan

- Diagnosis and physical status
- Current levels of functioning
- Medications and dosage
- Management instructions
- Physician's contact information
- Preferred hospital or urgent care facility
- Directions for transportation in emergencies

The Individual Child or Youth

- The physical and educational needs vary depending on the progression of their disease.
- Child/youth needs to be assessed regularly and results need to be shared with school staff.
- Encourage friendships and facilitate positive social skills in all arenas
- Staff orientation to JHD can increase compassion, patience, and extra support

Things to Consider...

- Not every school has a school nurse (R.N.)
- Include the school nurse or health assistant in IEP or 504 planning
- School counselors can provide strong support as well as a “safe haven”
- Orient staff on known symptoms of JHD so they can observe and report any changes (e.g. choking, seizures, aggressiveness)
- Be sure cafeteria staff, bus drivers, and playground attendants are informed as appropriate

Resources

- **NICHCY** (National Information Center for children & Youth with Disabilities)
www.nichcy.org
- **PACER CENTER** www.pacer.org
- **Technical Assistance ALLIANCE for Parent Centers** www.taalliance.org
- **Families and Advocates Partnership for Education** www.fape.org

Resources

- **The Huntington's Disease Association (HDA) Juvenile Huntington's Disease - Information for Schools** (The HDA is a UK registered charity)

<http://www.hda.org.uk/juvenile/schools.html>

- **The Family Guide Series: Juvenile Huntington's Disease**

Huntington's Disease Society of America

http://www.huntington-assoc.com/Juv._HD.pdf21

Resources

- To Find Your State Title V Program:
Health Resources and Services
Administration (HRSA), Maternal & Child
Health Bureau (MCHB)
<http://www.mchb.hrsa.gov/programs/default.htm>
- Family Voices <http://www.familyvoices.org/>